

University of San Diego

Digital USD

---

At Risk for Huntington's Disease

Department of History

---

6-14-2010

## Charting new territory: going public about HD

Kenneth P. Serbin  
*University of San Diego*

Follow this and additional works at: <https://digital.sandiego.edu/huntingtons>



Part of the [Nervous System Diseases Commons](#)

---

### Digital USD Citation

Serbin, Kenneth P., "Charting new territory: going public about HD" (2010). *At Risk for Huntington's Disease*. 70.

<https://digital.sandiego.edu/huntingtons/70>

This Blog Post is brought to you for free and open access by the Department of History at Digital USD. It has been accepted for inclusion in At Risk for Huntington's Disease by an authorized administrator of Digital USD. For more information, please contact [digital@sandiego.edu](mailto:digital@sandiego.edu).

# At Risk for Huntington's Disease

*HD is a genetically caused brain disorder that causes uncontrollable bodily movements and robs people's ability to walk, talk, eat, and think. The final result is a slow, ugly death. Children of parents with HD have a 50-50 chance of inheriting the disease. There is no cure or treatment.*

## Blog Archive

- ▶ 2021 (12)
- ▶ 2020 (16)
- ▶ 2019 (19)
- ▶ 2018 (16)
- ▶ 2017 (14)
- ▶ 2016 (13)
- ▶ 2015 (24)
- ▶ 2014 (24)
- ▶ 2013 (30)
- ▶ 2012 (26)
- ▶ 2011 (33)
- ▼ 2010 (26)
  - ▶ December (4)
  - ▶ November (1)
  - ▶ October (2)
  - ▶ September (3)
  - ▶ August (2)
  - ▼ June (2)
    - [Charting new territory: going public about HD](#)
    - [God, Huntington's disease and the meaning of life](#)
- ▶ May (3)
- ▶ April (2)
- ▶ March (2)
- ▶ February (2)
- ▶ January (3)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

## About Me

 [GENE VERITAS](#)

[View my complete profile](#)

## HD Links

[Huntington's Disease Society of America](#)

MONDAY, JUNE 14, 2010

## Charting new territory: going public about HD

On June 10, for the first time ever, I revealed in public that I am gene-positive for Huntington's disease.

It's been a long road – from the time I learned in late 1995 of my mother's diagnosis for HD, to the test in 1999 that changed my life forever, to the speech at which I had the courage to tell an audience that my mother died of HD and that I run the risk of developing the disease at any moment.

The reasons for not going public continued to loom like enormous storm clouds in the days and hours leading up to the speech that I gave at the [Catholic University of Rio Grande do Sul](#) in Porto Alegre, Brazil. By revealing that I would likely lose my ability to walk, talk, and think at some point in the next decade, I would be forever putting at risk the possibility of advancement in a field in which people highly prize research, writing, and speaking.

Now that I've opened up to others in public, I've thrown off my protective sheath of anonymity. I didn't realize how convenient, comfortable, and reassuring it was to have that anonymity. I could avoid controversy, and I could go on acting as if nothing would happen to me.

I now feel that I'm charting completely new territory in my life, the life of my family, and my involvement in the movement to stop HD. I have no way of knowing what triumphs and pitfalls await me. I fear that I won't be ready for them when they occur.

## Planning a trial run

In January I received an invitation from the Catholic University to speak on the theme of sustainable development. That's not my field, but as a frequent commentator on current events for Brazilian newspapers, I felt fully capable of working up a presentation.

Just days before I had completed the first draft of my previous blog entry, "[God, Huntington's disease and the meaning of life](#)," which featured a discussion of the life and writings of the Catholic Jesuit priest Teilhard de Chardin (1881-1955). Teilhard focused on ecological issues in parts of his work, and he has inspired more recent thinkers to embrace environmentalism.

I decided that in 2010 I would start going public. So I decided to use the speech to start getting the feel for life out of the HD closet.

I felt comfortable sharing my HD predicament, speaking in Portuguese, with a Brazilian audience. Brazil is a second home for me; I first traveled there in 1986 and haven't missed a year since.

At the same time, I felt that revealing my situation for the first time before an audience in a distant land was less risky than doing it in my own

[International Huntington Association](#)  
[Huntington's Disease Drug Works](#)  
[Huntington's Disease Lighthouse](#)  
[Hereditary Disease Foundation](#)  
[Huntington's Disease Advocacy Center](#)  
[Thomas Cellini Huntington's Foundation](#)  
[HDSA Orange County \(CA\) Affiliate](#)  
[HD Free with PGD!](#)  
[Stanford HOPES](#)  
[Earth Source CoQ10, Inc.](#)

## HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)  
[Angela F.: Surviving Huntington's?](#)  
[Heather's Huntington's Disease Page](#)

backyard. It's hard to explain, but it felt safer than coming out someplace closer to home like work, where I'm not yet ready to speak to people about HD. It would be a trial run for both a speech on my gene-positive status and the powerful feelings sure to surge up from within the depths of my being after so many years of public silence.

### The act of going public

About 250 people gathered in the auditorium for my speech. There were students, professors, and people from the local community.

After I provided some background on myself and some thoughts on 25 years as a historian of Brazil, I began by showing pictures of three people with HD. I explained that HD is a 100-percent genetic disease and that people with the defective gene all get sick. I described it as a combination of Alzheimer's and Parkinson's diseases. Huntington's, I explained, attacks the brain and robs people of their ability to walk, speak, think, and swallow.

Many HD people shake or have exaggerated movements. As a result, I continued, HD people are sometimes arrested by the police on suspicion of drunkenness. Standing at the podium, I tried to recreate the movements of an HD person by swaying left and right.

HD can go on for up to 20 years, I said. During that time the patient becomes increasingly dependent on relatives and caregivers.

The end is a difficult and sad death.

After describing the three pictures in detail, I put up a slide demonstrating MRI images of a healthy brain and another terribly compromised by HD, with large areas of white space where neurons had died.

There is no treatment or cure – only a few palliatives to reduce the effects of symptoms such as the uncontrollable movements. No medication attacks the disease's root causes.

### Getting personal

Without pause, I went on: my mother died of the disease in 2006. Because my wife and I wanted to have a child, I got tested eleven years ago this month. The result was positive.

"Tonight, before you in this beloved and honored land of Rio Grande do Sul, I am speaking publicly about my situation for the very first time," I said, my voice becoming more intense. "This means a lot, because it's been 15 years of anonymity – an anonymity imposed by the fear of genetic discrimination, a new discrimination created by the advances of science, which increasingly allow a person to know his or her future health profile, and discrimination also because denial and prejudice continue to impede the understanding and acceptance of people with disabilities."

I'm okay now, I told the audience. But the disease could start at any moment.

I finished the HD portion of the presentation by showing two photos I had taken illustrating the [Isis Pharmaceuticals, Inc., research for an oligonucleotide](#) that could become a potential treatment to attack the disease at its genetic roots.

During the conclusion of the speech, I returned to the theme of HD. "We face immense problems, from the cure of diseases such as Huntington's to the salvation of the planet from environmental destruction," I said. "But our capacity for research is also growing."

## Worrying about reactions

In the days before and after the speech I feared how people would react.

My wife, who is Brazilian, counseled me not to mix my work with personal life. It wasn't right, she said, to insert into the speech something that (apparently) had nothing to do with the requested topic. But the organizer of the event had given my wide discretion, and I believed that a personal reflection comparing the need for research on two critical problems facing humanity would capture the audience's attention.

Later, however, my wife came to understand my need to include HD. I reminded her that if we in the HD community won't even speak out for ourselves, then nobody else will have any reason to care about us. She agreed.

The morning of June 7, the day before I departed for Brazil (without my wife or daughter), I had an intense dream in which I had a very frank and amiable conversation with a cousin whose mother had kept him in the dark about my mother's condition until she died. In my waking life, I am extremely angry at this branch of the family for ignoring my mother. I awoke from the dream with the absolute conviction that I needed to come out about HD during my speech.

## The aftermath

It's impossible to know what people in a crowded auditorium are thinking about a speech. I noticed that people seemed riveted throughout the presentation.

After the speech, three commentators – Brazilian experts on sustainable development – offered their thoughts on my words. All three of them expressed solidarity with my situation, and one in particular thought my personal reflection was very important.

In a long question-and-answer session with the audience, however, nobody asked anything about HD. I was disappointed. Neither did the topic come up afterwards at a dinner with the organizer and two of the commentators.

This was probably the first time that anybody in the audience had heard of HD. Despite the increasing publicity, HD remains still a relatively unknown disease even in the U.S., compared with amyotrophic lateral sclerosis (Lou Gehrig's disease), Alzheimer's, Parkinson's, and muscular dystrophy.

Brazil is many years behind in awareness about neurological diseases. The [Huntington's Disease Society of America](#) has more than 30 chapters and 25 Centers of Excellence for Family Services and Research. However, Brazil, a country of nearly 200 million people and an estimated 20,000 HD people, has the equivalent of only two chapters, only incipient family services, and no research programs for treatments or a cure. The [Associação Brasil Huntington](#) was founded in 1997 and bravely seeks to assist HD families spread throughout a country larger than the continental U.S.

Also, the fact that I am currently asymptomatic undoubtedly reduced the impact of my comments on HD. If I were already showing symptoms, the presentation would have been infinitely more powerful.

One woman, though, left me a note with a little prayer card thanking me for the opportunity to hear me speak. "Don't forget that for God nothing is impossible!" she wrote. "May the size of the problem become small alongside the size of your faith!"

Another woman, an engineer, thanked me for my courage in speaking

about HD and for pointing out, via Teilhard, how everything in the world is interrelated. Lamenting the attitude of a colleague who doesn't want to consider his projects' impact on people, she agreed with me that everything we do has a social consequence.

### Unpredictable paths

After the speech I felt angry for a while at my colleagues. I asked myself: why didn't they want to know more about HD or my situation? But, thinking about it carefully, I understood that it wasn't fair to expect any further curiosity, given the general lack of knowledge about HD and the fact that the main theme of the speech did not deal with it.

Over the years my wife has regularly warned me about this. In fact, she worries deeply about how I will handle the lack of attention and maybe even rejection that will be part of a public stance about my gene-positive status.

Away from my family and friends in San Diego, I felt very lonely in Rio Grande do Sul.

When I revealed that I was gene-positive, no bells rang, no lightning struck. Coming out as I did is just one step by one person in the process of building awareness about Huntington's disease. It's a huge personal step for me, but the steps still will be even bigger and more important ones as I strive to keep healthy and do my part to the build the movement.

Before June 10, I was quite accustomed to acting as a behind-the-scenes advocate.

Now I gently leave behind that phase of my life to try out new and unpredictable paths.

### Moment by moment

No matter how widely known my gene-positive status becomes, I will continue to write in this blog under the pseudonym "Gene Veritas." The name has come to mean a lot to me and to many of the readers of this blog. It's a trademark – "the truth in my genes" – that reveals so much about my predicament and that of so many other people facing the possibility of a genetic disease. It also gives me the freedom to continue expressing myself freely about HD.

Going public about HD is a process for which there is no ritual or long history of examples. I'll learn as I go, finding the right formula and pace for me.

I have learned to take living at risk for HD day by day. For a while, at least, I will go moment by moment as I step further out of the HD closet.

Right now, I'm going to rest up from my trip and let tomorrow worry about tomorrow.

---

Posted by [Gene Veritas](#) at [12:17 PM](#)      

11 comments:

#### **sallycravens said...**

Gene, as I have told you over and over, I admire your courage. You make me raise my level of inspiration more and more, and I am even more determined in helping in whatever way I can in making this the last generation of HD. I love you and your

family, and know that the HDSA-SD Chapter is doing what we can to raise money and awareness for HD families.

Sally Cravens  
Board Member  
HDSA-Sd Chapter

2:42 PM, June 14, 2010

❁ **Anonymous said...**

Dear Gene, Over 50 years ago almost to the day my oldest sister got married. I was 15 and a bridesmaid. The plans for this wedding had been consuming my family for months. The morning of the wedding I remember riding in the car as we drove to the church to drop off the bridesmaids dresses we would don at the church in a few hours. We passed a friend going to play tennis. I thought "How very odd." That someone would be doing ordinary things on a day so momentous for me and my family seemed just wrong. This post reminded me of that day. Such an important day for you, but not for everyone else. To paraphrase the lady in Brazil--Your courage is bigger than your disease and your faith is bigger still. You give us strength. May God bless you and your family. Thank you.

Caroline

8:41 PM, June 14, 2010

❁ **Anonymous said...**

I am related to this disease through a non-blood relative, and had never heard of it until I met this person (they have kept this a secret so that I do not even want to indicate what gender they are for fear of giving something away -- this is the nature of the fear exposure brings for those with HD).

I have tried to explain the disease to other people from time to time and have come to the conclusion that no one can possibly grasp the enormity of its effects on the person and those who love them if they haven't had first hand experience.

I have walked with this dear soul, have wept, have shook my hands at the heavens, and have waited with them for "the bomb to drop" in the form of visible symptoms.

I work in public service and have dealt with many hurting people and every sort of life crises, but nothing has ever come close to the agonizing reality of HD.

I go at times to support meetings, unbeknownst to my precious relative, hoping to learn better how to care for them. I remember my first meeting where I heard family members of those with HD each share their own personal nightmares. I grieved all the way home, and wasn't sure I would ever come back.

The truth is, that until you either have HD or walk alongside someone dealing with it, you simply cannot appreciate what

this disease is like, and this is why so few responded to the incredible courage you demonstrated.

I want to thank you for all you do, and tell you that you will never know the lives you touch. The person with HD in my life is still in complete anonymity and is determined to stay that way -- the risk is just too great.

Someday I hope to share your blog with them -- the time hasn't been right yet, but I am continually encouraged and gain wisdom from your journey.

Please continue to be the trailblazer for those who cannot go ahead on their own.

8:57 PM, June 15, 2010



❁ **Confessions of a Mother, Lawyer & Crazy Woman said...**

Gene - You are strong and brave. I wanted you to know that. Thanks for sharing this post.

2:31 PM, June 16, 2010

❁ **Anonymous said...**

Congratulations, Gene.

I understand your anger that none of your colleagues seemed to care. When I say something really important for me, reveal something very personal, I want a response. But I'm learning that no response doesn't always mean a lack of concern or care. Sometimes they don't care, but more often they're scared or don't know how to talk about it. The telling is more often for me than them.

And yes, there is rejection. But I don't want people in my life who can't handle who I am. And this is who I am. You know? I don't know anything about Brazil but there may be a cultural thing about talking openly about illness as well.

Hang in there and keep writing. Congratulations. :)

Michelle

10:15 PM, June 16, 2010

❁ **Anonymous said...**

Dear Gene, I am not at risk physically but the love of my life is and she is starting to have some symptoms, she is afraid to get tested and I understand how devastating that is to know and then what? I feel that we both will be positive, she is my soul mate and I cannot imagine my life without her, without our conversations, without our walks, without our traveling, without our laughs, without her caresses, without our daily activities together, I cannot imagine life without her, I feel that we both will die slowly of HD but I will have to be strong for her

and take care of her, and give her all my love and soul. Mean while we need to do as much as we can possibly due to find a cure to stop this horrible disease that is taking so many at such a young age. I admire your courage and dedication, sometimes people are so touched that it is like a shock for them when they hear about HD and they don't ask questions because they feel that it is something very painful and sensitive, and they are afraid to ask the wrong questions, sometimes it is not because they don't care, specially if they know you. It has happened to me in like 3-4 occasions and it hurts my heart, but then they have approached me in private and then they ask questions. One thing that makes me very mad, are family members that offered you no support or they just don't care about anything that has to do with Huntington's Disease. I went to talk with one of my brother's in law about HD and my spouse and he didn't even allow me to finish my first sentence when he immediately told me that I needed to change the subject or that I needed to leave his house that it was all nonsense and that he was not interested in knowing about it. I was there thinking that his sister was as important to him, but he told me that we all have things in life that we have to deal with and that we all have our own family circle to deal with, I got up and left in tears, he said my name and I thought for a minute that his heart had soften and that he would apologize for his indifferent and cruel words, I turn my head around and he looked me in the eye and told me, not to ever come to his home to bother him and his family, and that he promised me not to tell my spouse that I had been there, otherwise she would be upset at me. Her mother said to me when her father died so did the disease it is no longer in our family so please don't you ever mention it again, you will only be wasting your time. It is hard to imagine to have been raised by people like that and yet be a wonderful person like my wife, she is my world, my life, my soul mate.

12:55 AM, June 17, 2010

🌀 **squirrely Matt said...**

I've been lurking for quite some time now, and just wanted to say Congratulations on the first steps to going public about your condition.

5:55 AM, June 17, 2010

🌀 **Errol Walsh said...**

Dear Gene,

Congratulations on your courage and determination!

This message of love and support comes to you from the HD family in Northern Ireland.

Errol Walsh

Development Officer  
Huntington's Disease Association Northern Ireland

7:29 AM, June 17, 2010

🌀 **Jimmy Pollard said...**

"The name has come to mean a lot to me and to many of the readers of this blog."

You're damn right it has!!!

Keep on keepin' on, Gene! It's a long road, indeed!

Jimmy Pollard

11:50 AM, June 17, 2010

🌀 **Anonymous said...**

Gene,

My husband passed away 3 yrs ago with HD. I understand your comments so completely.

I remember telling a co-worker about my husband's diagnosis, and he responded, "Oh, I know what you are going through. You see, our family has a genetic illness, and I am diagnosed with the problem. I have psoriasis?"

My inner soul wanted to hit him! Thank you for helping to spread awareness.

Jean

12:17 PM, June 20, 2010

🌀 **Anonymous said...**

hi gene,im from brazil and my mother sha has the hd and i did the test and i do have too....im feel lost ,i dont know so much about the hd and i hope for the cure ,im 33 years old and im pregnant now....but god knows everything...god bless youu

9:05 AM, June 27, 2010

[Post a Comment](#)

[Newer Post](#)

[Home](#)

[Older Post](#)

Subscribe to: [Post Comments \(Atom\)](#)

---